

Mental Retardation: Management and Prognosis

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Walker did not
disclose any financial
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To view an Appendix
entitled "Listings for
Organizations Discussed
in Text," go to
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this article.

Note: This is part 2 of a 2-part article. Part 1 appeared in the June 2006 issue.

Objectives After completing this article, readers should be able to:

1. List key components of the special education system that benefit children who have mental retardation (MR).
2. Describe associated conditions that commonly occur in children who have MR.
3. Recognize the importance of family supports, including support of siblings, in the management of children who have MR.
4. Discuss the most likely adult outcomes for persons who have various levels of MR.
5. Delineate the factors, in addition to cognitive skills, that help determine long-term outcomes of persons who have MR.
6. Know when it is appropriate to pursue guardianship proceedings for an adult who is mentally retarded.

Overview

Management of mental retardation (MR) begins with breaking the news to parents of affected children sensitively, compassionately, and culturally appropriately. It is important to emphasize the child's strengths in addition to describing the delays or deficits. It also is important to be realistic without taking away hope. If the child is younger than 6 years of age at the time of diagnosis, it may be more appropriate to use the term "global developmental delay" unless the delays are due to a recognizable syndrome known to be associated with MR. When the child enters elementary school and standardized testing provides more reliable and predictive results of adult cognitive impairment, the diagnosis may be revised to "mental retardation." Parents should be informed that the child will continue to progress, albeit more slowly, than his or her peers. Families need additional patience and persistence when raising a child who has MR. Unlike typically developing children, who seem to learn skills simply by modeling their parents, siblings, and peers, children who have MR may need specific instruction to master a skill. If the global developmental delay or MR is due to a known syndrome, appropriate genetic counseling and up-to-date literature should be provided. A referral to a genetic or a developmental specialty clinic may be helpful.

The primary focus of management for a child who has idiopathic global developmental delays or MR is educational. Educational services should begin as soon as the delay or deficit is recognized and be delivered in integrated settings with typically developing peers to the greatest extent possible. As with any child, children who have MR benefit from comprehensive health care within the context of a "medical home." If the child has a known syndrome, the clinician needs to address any medical complications that are characteristic of that syndrome (eg, thyroid disorders in children who have Down syndrome [DS]). Behavioral challenges may need to be addressed in both educational and health care systems.

Support of parents, especially respite, is very important. As the child enters adolescence, issues relating to sexuality, transition into adulthood, and guardianship (if the level of MR is severe) need to be addressed. The parents should foster the child's independence throughout the lifespan as much as possible.

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Educational Services

The most recent reauthorization (2004) of the Individuals with Disability Education Act (IDEA) continues the nearly 30-year commitment of the federal government on behalf of children who have special needs to receive necessary and appropriate educational services in the “least restrictive environment (LRE).” Each state has its own organizational structure to provide this spectrum of services at the local level: early intervention services, school-age services, transition services.

Children diagnosed prior to their third birthday should be referred to an Early Intervention Program (EIP). An infant diagnosed with a syndrome known to be associated with MR (eg, DS) becomes eligible for such support services at the time of diagnosis, even though delays may not yet be evident; children who have no recognizable syndromes are not eligible until delays are identified. The child should be referred to EIP as soon as delays are noted, even though an etiologic evaluation still may be in progress. On referral, the child is scheduled for a multidisciplinary team evaluation to confirm eligibility and to serve as the foundation for development of an Individualized Family Service Plan (IFSP). The services available through the IFSP may vary from state to state, but most programs offer case management, family support, parent training, and some direct therapy (speech, occupational, and physical). The cost is free in some states; in others, the child’s insurance plan may be billed or the parents may be required to pay a sliding scale fee based on family income. When designing the IFSP and defining services for the child, both the team and the parents should consider the needs and wishes of the entire family.

More often, children who have MR, especially mild-to-moderate MR, are not identified until after their third birthdays. At this point, the clinician should refer the child to the special education department at the local school. Children ages 3 to 6 years of age usually are served in the “Preschool Program for Children with Disabilities (PPCD).” A team evaluation serves as the basis for an “Individualized Education Plan (IEP),” a detailed description of a child’s abilities and deficits as well as the methods and measures that will be used to intervene and monitor improvement. In addition to free public education, the child may receive necessary speech, occupational, or physical therapy, as outlined in his or her IEP. Therapeutic services provided by schools, unlike rehabilitative therapy in hospitals, address only those skills necessary for success in academic activities. Often, the therapy is “consultative” rather than “hands-on” or “direct.” This means that the therapists periodically eval-

uate the child’s progress, reconfirm or update (depending on the child’s progress) the therapy goals and objectives, and provide the teachers or aides with individualized strategies to promote skill attainment.

When the child makes the transition to elementary school, another evaluation is conducted to determine whether special education services still are needed. In addition to describing the type, intensity, and frequency of the services recommended, the team determines the best setting(s) for delivery of the services. This information is consolidated in the IEP. Children who have disabilities appear to have better outcomes when they are included in regular classrooms with typically developing peers. The extent of inclusion may depend on the level of MR as well as the presence of associated conditions, especially maladaptive behaviors (aggression, self-injurious). It also depends on the school district’s resources. The child should be included in all extracurricular activities and nonacademic classes and, whenever possible, in as many academic classes as is feasible. Although the LRE principle is very important, inclusion in a regular classroom never should prevent the child from receiving the specialized services outlined in the IEP.

In high school, skills needed for successful independent living and meaningful employment should be targeted. When the teen approaches 16 years of age, an evaluation is performed to develop an Individualized Transition Plan (ITP). The ITP meetings differ from the IEP ones in that: 1) the students are allowed to attend and participate in the decision-making process, 2) the emphasis changes from academic activities to vocational training in the most appropriate job setting (competitive, supportive, sheltered workshop), 3) the focus of services targets the teen’s interests and abilities rather than deficits and remediation, and 4) representatives from adult-oriented agencies are invited and asked to provide input regarding postgraduation services and training opportunities.

Inclusion in extracurricular and social activities becomes more important in maintaining self-esteem as the child ages. Whereas younger children usually are not excluded from integrated play with typically developing peers, older children who have MR have fewer opportunities for social interaction. Students who have MR often benefit from participation in a regular athletic program, such as Special Olympics. These programs not only promote physical health and fitness, but they improve self-esteem and self-worth and provide opportunities for socialization and leadership. As with academic and vocational services, disruptive behavior may prevent the child from being included at social and athletic events.

Children who have disabilities may attend public school through 21 years of age. Usually such attendance reflects prolonged training opportunities in vocational or life skills during the high school years rather than actual grade retention. Grade retention occasionally may be indicated in very young preschool or elementary students, especially when a child has a late birthday, is immature, or is small for age. However, retention generally is discouraged later in the school career due to its adverse effects on self-esteem and long-term outcomes, as reflected by increased rates of dropping out of high school and juvenile delinquency.

Health Maintenance

As with typically developing children, children who have MR benefit from ongoing health care within the context of a “medical home.” Unfortunately, the quality of health care for persons who have MR frequently is below established standards. Health care should be family-centered, accessible, continuous, comprehensive, culturally sensitive, and developmentally appropriate. Parent-professional partnerships are especially important for children who have chronic disorders such as MR. In addition to the child’s needs, the needs of the parents always should be considered in medical decision-making. Except for the extra time and effort needed to communicate with schools and community agencies, the routine health maintenance of children who have idiopathic mild MR is very similar to that of typically developing children. The clinician should place special emphasis on safety issues, attainment of future developmental milestones, prevention of behavior problems, and early and ongoing promotion of independence. Dental, vision, and hearing surveillance and preventive care are vital aspects of health maintenance.

During adolescence, the pediatrician needs to address such issues as masturbation, inappropriate sexual behaviors, contraception, and hygiene associated with menstruation among individuals who have MR, just as he or she would with individuals who are not mentally retarded. Although participation of the parents may be greater and the explanations more basic, the patient’s interests, desires, and cultural and religious beliefs must be considered. Parents of individuals who have MR often express concerns about the possibility of pregnancy or sexual abuse and the efficacy of birth control methods. In

addition to traditional 30-day cycle oral contraceptives, newer, more convenient methods of long-term contraception are now available. These include weekly applied transdermal patches, monthly intramuscular injections, 91-day extended cycle packs (ethinyl/estradiol/levonorgestrel: 84 active, 7 inert), implants that are effective up to 5 years, and long-term progestin-releasing intrauterine devices that can provide protection for up to 10 years.

If the child has a known syndrome, the clinician needs to address any medical complications that are characteristic of that syndrome and to monitor for associated secondary conditions (eg, a thyroid disorder or atlanto-axial subluxation in DS) and prevent complications when possible. If no cause has been identified to explain the child’s MR, an additional “search” might be indicated when new technology is available.

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Comorbidities

Children who have MR, especially those whose forms are more severe, often have associated physical, medical, and emotional conditions that affect their well-being, sometimes to a greater degree than the cognitive deficits. An associated disorder (comorbidity) might be the presenting finding that prompts a thorough evaluation that, in turn, reveals cognitive deficits consistent with MR.

Behavior Challenges

As the intelligence quotient (IQ) decreases, the prevalence of behavior problems increases, approaching 50% in those who have severe MR. When assessing whether a particular behavior is inappropriate, the clinician should consider the child’s mental rather than chronologic age. For example, behavior representative of the “terrible 2s” in a first grader who has severe MR may reflect an expected challenge that is consistent with developmental progress and, therefore, should not be considered “inappropriate.” Behavior management strategies often are a key element of the IEP for children who have severe MR. Some challenging behaviors may be so disruptive that medication might be indicated as a component of com-

prehensive management. If the primary care physician does not feel comfortable initiating medication treatment, referral to a developmental pediatrician or a child psychiatrist can be helpful. Antiepileptic drugs may be effective in treating irritability and mood swings. Some neuroleptics (especially newer generation ones that have fewer adverse effects) and alpha-2-adrenergic agonists (clonidine and guanfacine) may be helpful when aggression, self-injurious behaviors, and stereotypies exist. The clinician never should initiate medical treatment without considering the negative impact that such medications might have on habilitative function, such as sedation while the individual is undergoing vocational training.

Psychiatric Disorders

“Dual-diagnosis” currently is defined as a specific mental illness occurring in a person who has MR. Frank mental illness now is recognized as being more common in individuals who have MR, especially severe forms, than in the general population. The more common comorbid psychiatric disorders include attention-deficit/hyperactivity disorder (ADHD), anxiety, depression, obsessive compulsive disorder, oppositional defiant disorder, and less commonly, schizophrenia. Diagnosing such conditions in persons who have MR is more challenging due to a lack of reliable assessment tools and poor communication skills of the affected person. Stimulant therapy for children who have MR and significant ADHD symptoms may not be as successful as in children who have no additional neurodevelopmental disorders. The selective serotonin reuptake inhibitors (SSRIs) may be helpful for children who have anxiety, depression, or obsessive compulsive disorder. It is unclear whether the recent concerns about the safety of the SSRIs apply to teens who have MR and markedly lower mental ages.

Seizures

Seizure disorders are approximately 10 times more common in children who have MR, especially in those whose impairments are severe. Often, the seizures are more challenging to control than those in typically developing children due to underlying syndromes, central nervous system pathology, and the coexistence of multiple seizure types in a single patient. If a child is prone to status epilepticus, an emergency protocol should be established, which may include instruction in rectal administration of anticonvulsants at home and at school.

Sensory Impairments

Hearing and vision impairments also are more common in children who have MR, especially in those who have

comorbid craniofacial syndromes. Approximately 50% of children who have severe MR have visual deficits, the most common being strabismus and refractive errors.

Motor Impairments

Approximately 10% of individuals who have mild MR and 20% of those who have severe MR have significant motor deficits consistent with cerebral palsy. Approximately 50% of children who have cerebral palsy have comorbid MR of some degree. There is some, but no absolute, relationship between the type of cerebral palsy and the severity of MR. The relationship is much stronger in children who have severe spastic cerebral palsy than in those who have dyskinetic forms. The impact of a motor impairment on performance should be considered during any neuropsychological evaluation.

Sleep Disorders

Like behavior problems, the prevalence of sleep disorders is inversely proportional to intelligence. Many children who have severe MR have a sleep disorder. Often, the most severe consequence of a sleep disturbance is the resulting physical and emotional burden on the child's family and caretakers. Poor sleep is associated with poor daytime learning, poor occupational performance, and increased daytime behavior disorders, especially aggression and self-injurious behavior. As with other children, management begins with behavioral strategies to improve sleep hygiene, such as the implementation of consistent bedtime rituals. Biologic interventions include melatonin and medications. Melatonin has been widely studied in children who have disabilities and has been found to be very helpful in both inducing and prolonging sleep. Because melatonin is not approved by the United States Food and Drug Administration, there is high variability among brands. Short-acting preparations may be used when the child has difficulty falling asleep and long-acting ones for children who wake at night frequently. Some medications (eg, antihistamines, sedatives, clonidine) can be used on a long-term basis, while others (zolpidem tartrate) are best reserved for older patients and short-term use during vacations, camp, or visits to friends and relatives.

Recurrent Vomiting

Emesis may indicate a medical condition such as gastroesophageal reflux or, in rare cases, may be the presenting feature of an underlying metabolic disorder. In a nonverbal child, it often is an expression of anger, frustration, or anxiety. Thus, the first challenge is to discern whether the cause of the emesis is organic or behavioral. This may

require the coordinated efforts of a gastroenterologist, a developmental pediatrician, and a child psychologist or other behavior specialist.

Autism

If social skills, particularly joint attention skills, are significantly more delayed than those in other developmental domains, the child who has MR may meet full criteria for autism. Ideally, a team evaluation using an autism-specific diagnostic instrument is needed to differentiate whether the child is primarily mentally retarded and demonstrating some autistic symptoms or is primarily autistic and has comorbid MR. Approximately 50% to 75% of individuals who have autism have some degree of MR. Autisticlike behaviors alone (eg, stereotypies, self-injurious behaviors) are not diagnostic of autism; they may be seen in some children who only have MR, especially those in whom MR is severe.

Family Support

Parents are every child's most important resource, but their importance is magnified for individuals who experience a prolonged, or even persistent, period of dependency. Providing support to parents in their caregiving role is a very important function of the primary care physician. A family's requirement for community support depends not only on the characteristics of the child's degree of cognitive impairment, level of independence, and behavioral challenges, but on structural (eg, single-parent household), functional (eg, coping strategies), and external (eg, income and work schedules) characteristics of the family. There are two levels of community supports: informal and formal. Informal supports include: community organizations that provide advocacy, parent training, counseling, child care, respite, or recreational activities and social networking with other families through parent support groups and, most recently, through the Internet. Formal supports include publicly supported programs to which families are entitled. Early intervention and public schools, particularly special education programs, are entitlement programs for all children who have MR.

Other public programs are not available to all children who have MR but rather depend on both the degree of disability and the family's financial status. These supports include supplemental Social Security Income (SSI) stipends, Medicaid benefits, and "waiver" vouchers. Most adolescents who have MR, especially those whose MR is severe, become eligible for both Medicaid and SSI benefits when they turn 18 years old. At that point, financial eligibility no longer depends on the income of the par-

ents but solely on the income of the adult who has MR. They remain eligible throughout adulthood if they are unable to support themselves.

Waiver programs provide families with financial assistance to purchase wraparound services such as respite, home modifications, van adaptations, transportation, and recreational services. These programs usually are administered by state agencies (ie, state departments of health, human services, mental retardation, or disability) and have long waiting lists. Parents should be encouraged to contact the agencies so their child can be added to the list as soon as a significant disability becomes evident. When a "slot" becomes available (often several years later) and the child is approved for services, the family's income is waived and the child also becomes eligible for Medicaid benefits. Additionally, a case manager assesses the impact of the child and his or her disability on the family and determines the degree of monetary support the agency will provide, usually in thousands of dollars each year. These funds can be used to purchase respite or other needed wraparound services.

There are critical periods when parents, who otherwise are coping fairly well, need extra support. Usually, these represent times of major life-status transitions, when the child's "differences" are most obvious. Early in the child's life, these include the periods when the diagnosis initially is made, when a younger sibling developmentally "passes up" the child who has MR, and when the affected child first enrolls in special education. Additional critical periods include the onset of puberty (especially when it is associated with the escalation of behavior problems or the new onset of inappropriate sexual behaviors), graduation from high school (especially in the absence of vocational opportunities or community supports), transition from pediatric to adult health-care practitioners, determination of guardianship on the 18th birthday, or death of the custodial parent(s). Coping skills also are challenged if the teen is excluded from typical "rights of adolescent passage," such as social or athletic events, independent dating activities, and driver education classes.

Most parents desire to raise their child who has MR at home. However, critical periods such as those mentioned previously can overburden coping skills. Lack of community supports during these times of stress may prompt the parents to consider out-of-home placements. In the past, institutionalization was an option. Since the passage of the Americans with Disabilities Act in 1990, state facilities have been closing. A *Healthy People 2010* goal (see Part 1 Suggested Reading in June 2006 *PIR*) is to reduce the number of people who have disabilities in congregate

care facilities “to 0 by 2010 for persons aged 21 years and under.” The American Academy of Pediatrics supports this goal and has published a clinical report for pediatricians entitled *Helping Families Raise Children with Special Health Care Needs at Home* (see Part 1 Suggested Reading in June 2006 PIR). When out-of-home placements are deemed necessary, foster, adoptive, or shared-parent families are advocated. Permanency planning principles such as those that have been found to be beneficial to children served within child protective systems also should be implemented.

The impact of having a sibling who has MR can be both positive and negative. Anecdotal accounts abound describing the positive impact of being raised in a family that includes a member who has MR. Siblings have been noted to be more sensitive and mature, more tolerant of human differences, and more effective advocates for disability issues. However, there are some negative effects. Siblings may feel that they need to compete for their parent’s attention, especially when the child who has MR also has significant medical or psychiatric comorbidities. Others may perceive increased parental expectations and struggle to be a high achiever to compensate for the child who has MR. Unless the parents have adequately explained MR, siblings might have misconceptions about the cause of MR and fear that they will “catch” the disability. An older or a younger sibling (if she or he has “passed-up” the child who has MR) may be expected to act as a surrogate parent and, thus, undergo an accelerated passage to adulthood at the expense of some beneficial childhood experiences. Finally, siblings, even at a young age, may harbor concerns that they will be expected to care for the adult who has MR after the parents have died. Thus, pediatricians should be concerned about siblings and practice vigilance for their well-being.

Besides becoming eligible for SSI and Medicaid on their 18th birthdays, teens who have MR automatically become their own legal guardians. If parents and the professionals working with the individual do not feel that the patient is capable of making responsible decisions, a formal evaluation should be performed to determine the need for guardianship. This process should be pursued with great care because guardianship contradicts the values of self-determination and should be approached cautiously, especially when the adult’s deficits are milder. If guardianship is in the individual’s best interests, legal aid services should be sought to help the parents navigate the judicial system and to designate a legal guardian for the individual. The designee(s) might be one or both parents or an adult sibling, a relative, a family friend, or a professional.

Parents of children who have any disability should

develop a long-term financial plan that includes a “Special Needs Will and Trust.” The will must include a statement that the inheritance may be spent only on items and services that are *not* otherwise covered by federal subsidies (ie, Medicaid/Medicare and SSI) to which the individual who has MR is entitled. Otherwise, on receipt of the inheritance, the individual loses the federal benefits and even may be required to repay the government for services received in the past. The inheritance must be “spent down” to meet financial criteria and again become eligible for all benefits.

Prognosis

Parents often inquire about long-term prognosis at the time of diagnosis. It is very difficult to predict outcomes in very young children. The prediction may be somewhat easier in children who have known genetic syndromes for which long-term outcome studies exist. Substantial variability exists in developmental/intelligence test scores from early childhood until about 8 to 10 years of age. At that point, serial testing usually demonstrates a consistent developmental velocity, and the predictive value is enhanced. Most children who have idiopathic MR, especially those whose impairments are mild, learn at a steady rate; if regression occurs, the clinician should suspect the new onset of an associated comorbid disorder or consider the possibility of an undiagnosed degenerative disorder. Although intelligence is very important in determining prognosis, other factors may affect functioning and foster drastically different outcomes. These influences include environmental factors and coexisting behavioral, psychiatric, medical, and sensory disorders. Parenting style (ie, the provision of opportunity, fostering of well-being, and promotion of stability) also may affect the child’s ability to function independently. With increasing age, social and adaptive skills assume a greater importance in determining an individual’s independence and ability to function successfully in the community.

As noted previously, most affected individuals have mild MR. In the absence of comorbid disorders, such individuals can be expected to learn at one-half to two-thirds normal velocity and achieve a 3rd- to 6th-grade reading level by late adolescence (Figure). During high school, they usually are enrolled in the vocational track; with good work habits, they can be expected to be gainfully employed in competitive unskilled, semi-skilled, or in some cases, skilled jobs. They often are self-supporting, marry, and parent children. As with parents who have normal intelligence, they, too, may benefit from periodic parent training and support, especially during stressful times.

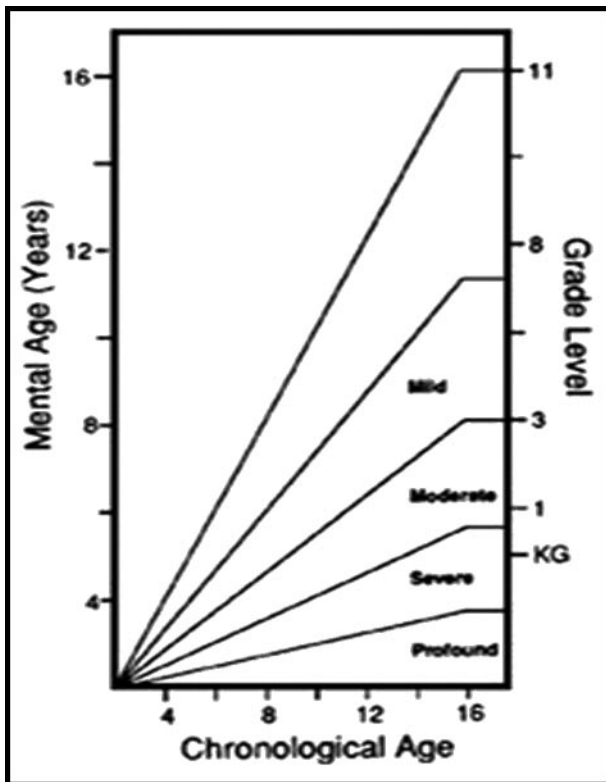


Figure. Progress of learning based on severity of mental retardation. Reprinted with permission from Accardo PM, Capute AJ. Mental retardation. In: *Developmental Disabilities in Infancy and Childhood*. Baltimore, MD: Paul Brookes Publishing Co; 1996:211.

Outcomes are not as optimistic for those whose MR is severe. Individuals whose IQs are between 40 and 55 (moderate) learn at one-third to one-half velocity and can be expected to achieve a 1st- to 3rd-grade reading level. They often live in group homes. They rarely marry and parent children; if they do, they likely need continuous support and supervision. They may be able to function in a supportive employment setting, but more often work in sheltered workshops that provide constant supervision.

For those whose MR is severe and profound (IQs 40 and below), the outcomes are even less optimistic. With great effort, some higher functioning individuals might be taught survival sight-reading (ie, “stop” and “exit” signs). They usually attend life skills classes during their school years and may continue to need help with activities of daily living from caregivers throughout adulthood. These individuals often have comorbid behavioral or psychiatric problems and need around-the-clock supervision. There is a higher prevalence of medical comorbidity; thus, unlike individuals whose MR is milder, life expectancy may be significantly decreased.

Conclusions

Management of MR begins with breaking the news to parents compassionately, followed immediately by a prompt referral to an infant EIP or, for older children, to a public education system. Children who have MR should be cared for in the context of a medical home and receive ongoing quality medical, dental, and mental health surveillance, with heightened vigilance for comorbid and secondary conditions. It is important to consider the well-being of all family members and help them identify and access needed public and community supports. Regardless of the degree of MR, parents should be encouraged to promote independence to the maximum extent possible throughout all stages of development and to begin long-term financial planning early in the child’s life. The primary care physician plays an important role in promoting health and independence, preventing secondary disabilities, supporting parents and siblings, and transitioning the adolescent to adult systems of care. Because mild MR is much more common than severe forms, most adults who have MR can be expected to live independently, have families, and be gainfully employed.

Note: See Suggested Readings in Part 1: Mental Retardation: Overview and Diagnosis in June 2006 *Pediatrics in Review*.

PIR Quiz

Quiz also available online at www.pedsinreview.org.

5. A 4-year-old child is suspected of having mental retardation (MR). Currently, the *best* term for describing this child's suspected condition at this age is:
 - A. Deficit development.
 - B. Delayed development.
 - C. Global developmental delay.
 - D. Mental retardation.
 - E. Slowed development.
6. It is established that a child who has MR should receive educational services as early as possible once the diagnosis is recognized. An Early Intervention Program (EIP) should be implemented in children diagnosed with MR before the age of:
 - A. 3 years.
 - B. 4 years.
 - C. 5 years.
 - D. 6 years.
 - E. 7 years.
7. For children who have severe MR and are receiving an Individualized Education Plan (IEP), a key element in this program is:
 - A. Adrenergic agonists.
 - B. Behavior management strategies.
 - C. Individual tutoring.
 - D. Psychological counseling.
 - E. Seizure medication.
8. A 2-year-old boy recently was diagnosed as having severe MR. His parents ask you about the risks of their child having seizures in the future. You tell them that their child's seizure risk is increased:
 - A. Two times.
 - B. Four times.
 - C. Six times.
 - D. Eight times.
 - E. Ten times.
9. The parents of a child who has severe MR are placed in a difficult position of providing for their child's ongoing emotional and financial needs. You have been asked to speak to a local chapter of parents of children who have MR concerning their needs. You advise these parents that most of their children, especially those who have severe MR, will become eligible for both Medicaid and supplemental Social Security Income regardless of their parents' income level at the age of:
 - A. 10 years.
 - B. 12 years.
 - C. 14 years.
 - D. 16 years.
 - E. 18 years.